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FACT SHEET

DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT (D.D. ACT)

Background

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) is the fundamental law supporting and enhancing the lives of people with developmental disabilities and their families. For over 30 years, the DD Act has enjoyed strong bipartisan support. It was last authorized in 2000, and is therefore long overdue for reauthorization.

Title I of the DD Act focuses on the estimated 5.4 million children and adults in the United States and territories who have developmental disabilities. The Act provides federal financial assistance to states and public and nonprofit agencies to support community-based delivery of services to persons with developmental disabilities to create and enhance opportunities for independence, productivity, and self-determination.

The DD Act consists of four programs that create an intersecting network. Grant funds support initiatives in civil rights protections, education and early intervention, child care, health, employment, housing, transportation, recreation, family support, and other services. The DD Act components are:

State Councils on Developmental Disabilities (DD Councils)

Councils on Developmental Disabilities are located in every State and Territory and include volunteers who are appointed by Governors. More than 60% of these volunteers must be people with developmental disabilities or family members. Councils are charged by Federal law to identify the most pressing needs of people with developmental disabilities in their State or Territory and to develop innovative and cost effective ways to address those needs in a manner that upholds the dignity and value of people with developmental disabilities. Councils work to promote the independence and productivity of people with developmental disabilities and promote systems change that will eliminate obvious inequities in areas such as employment, education, and access to healthcare.

Protection and Advocacy (P&A) systems

Under the Protection and Advocacy for Persons with Developmental Disabilities (PADD) program, P&As are required to pursue legal, administrative, and other appropriate remedies under all applicable federal and state laws to protect and advocate for the rights of individuals with developmental disabilities. Collectively, the P&A network is the largest provider of legally based advocacy services to people with disabilities in the United States. The federally mandated P&As serve individuals with a wide range of disabilities by guarding against abuse; advocating for basic rights; and ensuring accountability in health care, education, employment, housing, transportation, and within the juvenile and criminal justice systems

University Centers for Excellence in Developmental Disabilities (UCEDDs)

The DD Act authorizes core funds to 67 UCEDDs, at least one in every state and territory, that are components of a university system or are public or not-for-profit entities associated with universities. UCEDDs provide interdisciplinary training to students and professionals, engage in cutting-edge research, provide technical assistance, and direct services and supports to people with disabilities of all ages and their families. UCEDDs share information and research findings.

Projects of National Significance (PNS)

PNS is a discretionary program that focuses on emerging areas of concern. This program supports local implementation of practical solutions and provides results and information for possible national replication. PNS also supports technical assistance; research regarding emerging disability issues; conferences and special meetings; and the development of Federal and state policy. Additionally, funding is provided for states to create or expand statewide systems change.

Family Support Programs

Title II of the DD Act authorizes the Family Support Program to promote and strengthen the implementation of comprehensive State systems for in-home supports for families caring for individuals with disabilities. Family support services are effective in reducing the costs associated with life-long disability, and in preventing the expensive of out-of-home placement. However, this Title needs its own line item funding (\$15M.)

Action Taken by Congress and the Administration

No bills have been introduced to reauthorize the DD Act to date. The Administration recommended flat funding in FY 2010 and again for FY 2011 for DD Act programs (the FY 2010 Omnibus Appropriations Act passed by Congress and signed by the President in December, 2009 included modest increases in funding for DD Act programs)

Recommendations

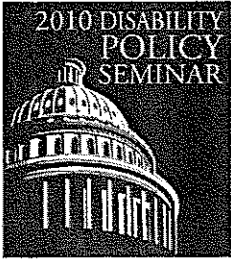
1. Congress should provide a significant increase in appropriations over FY 2010 levels for DD Act programs so that these programs can continue to respond to the needs of people with disabilities. With state budget cuts and inflation, these programs struggle to meet the demands of the growing population of people with developmental disabilities who experience multiple barriers to get and keep jobs, an education, and appropriate community based supports and services.
2. Congress should work toward timely reauthorization of the DD Act that:
 - Increases the funding authorization levels for the programs under the Act to expand the capacity of the DD Network and Family Support
 - Supports a separate title and funding authorization level (above and beyond funding for existing DD Act Programs) for self-advocate-directed Training and Information Centers.
 - Reauthorizing Title III – Preparation of Direct Support Professional Workforce to provide grants to states for personnel preparation, model demonstrations and systems change projects to improve the recruitment, training, support and retention of a qualified direct service professional workforce in each state.

Relevant Committees

House and Senate Appropriations Committees
House Energy and Commerce Committee
House Education and Labor Committee
Senate Health, Education, Labor and Pensions Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or Self Advocates Becoming Empowered (802) 760-8856.

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EDUCATION

Background

The U.S. Congress may complete work on two key education laws in 2010: the Elementary and Secondary Education Act (known as No Child Left Behind) and the Preventing Harmful Restraint and Seclusion in Schools Act. Both pieces of legislation impact the education of students with disabilities.

The Elementary and Secondary Education Act (ESEA), called "No Child Left Behind" in its last reauthorization, requires that all students be assessed to determine educational progress by individual schools and school systems. The disability community continues to support ESEA because the law requires the inclusion of all students with disabilities in the student achievement system. ESEA's authority expired in September 2007, and Congress is expected to begin work on reauthorization this year. There has been much controversy about how to measure educational progress for students with disabilities, a population that is frequently blamed by educators for their schools' poor test scores. The Bush Administration adopted two regulations aimed exclusively at certain students with disabilities. The first rule allows up to 1% of all students (10% of special education students) with significant cognitive impairments to be assessed using alternate assessments based on alternate standards. The other rule, not yet fully implemented, allows for assessments based on modified achievement standards aligned to the general curriculum for those students with disabilities (up to 20%) who can make progress toward, but may not reach, grade-level achievement standards in the same time frame as other students. The U.S. Department of Education has also allowed the states to employ so-called "growth models" to assess student performance (growth models seek to measure a student's progress within a certain timeframe).

The Preventing Harmful Restraint and Seclusion in Schools Act is pending legislation that would establish federal minimum standards limiting the use of restraint and seclusion in schools. Research and recent reports show that restraint and seclusion in education are often unregulated and used disproportionately on children with disabilities, frequently resulting in injury, trauma, and even death. In January 2009, the National Disability Rights Network issued a report detailing the harmful use of these interventions in over two-thirds of the states, involving children as young as three years old in both public and private school settings. Following that report, the Government Accountability Office (GAO) conducted an investigation finding no federal laws restricting the use of these interventions in schools, and that state laws vary widely if they exist at all. Restraint and seclusion are often used for behaviors that do not pose danger or threat of harm, and are implemented by untrained school personnel. Numerous alternatives to restraint and seclusion exist, including positive behavioral interventions and supports and other methods for preventing and stopping problem behaviors.

Action Taken by Congress and the Administration

Congress has begun the work of reauthorizing ESEA by holding hearings on the topic, but House and Senate leaders have yet to introduce bills to begin the reauthorization process. The Obama Administration released its blueprint for ESEA reauthorization in March. The blueprint provides incentives for states to adopt academic standards that prepare students to succeed in college and the workplace and create accountability systems that measure student growth toward meeting the goal that all children graduate and succeed in college. Although the Administration acknowledges that the primary funding for programs that support students with disabilities is through the Individuals with Disabilities Education Act (IDEA), it promises that its proposal will "increase support for the inclusion and improved outcomes of students with disabilities".

On December 9, 2009, Representatives George Miller (D-CA) and Cathy McMorris-Rodgers (R-WA) introduced H.R. 4247, the Preventing Harmful Restraint and Seclusion in Schools Act. On the same day, Senator Christopher Dodd (D-CT) introduced S. 2860, a companion bill by the same name. On March 3, 2010, the House passed H.R. 4247, renamed the "Keeping All Students Safe Act", by a bipartisan vote of 262 to 153. Both the Senate bill and the House-passed bill have been referred to the Senate Committee on Health, Education, Labor and Pensions and are awaiting further consideration.

The House and Senate versions of the bill are very similar. They establish federal minimum safety standards to limit the use of restraint and seclusion in public and private early childhood, elementary and secondary schools that receive any form of support from federal education funds, as well as Head Start programs. The bills ban the use of mechanical and chemical restraints, physical restraints that restrict breathing and aversive interventions that compromise health and safety.

The bills limit the use of physical restraint and seclusion to circumstances when a student's behavior poses an imminent danger of physical injury and less restrictive interventions would be ineffective, and require the cessation of the intervention when the danger has ended. School personnel who implement physical restraint and seclusion must be trained and certified, and must continuously monitor students during interventions.

The bills prohibit physical restraint and seclusion being written as planned interventions in individual student education documents, but allow for classroom and school crisis plans. Schools are required to establish procedures to be followed after restraint or seclusion are used, including parental notification. The Senate bill requires the school to have a debriefing session with the student's parents to discuss the incident.

The bills give each state two years to provide assurances that they have policies and procedures in effect that meet or exceed the minimum standards, as well as mechanisms to monitor and enforce the standards. States are also required to report the number of restraint and seclusion incidents in the state on an annual basis. The bills also provide for a discretionary grant program to assist states, districts and schools to establish, implement and enforce state standards, support data collection and analysis, support staff training, and improve school climate and culture through the implementation of school-wide positive behavior supports.

Recommendations

The 111th Congress should:

Restraint and Seclusion legislation:

- Pass the Senate bill and ultimately pass a final bill that establishes federal minimum safety standards for the use of restraint and seclusion in schools;
- Ensure that a final bill includes the prohibition of restraint and seclusion in a student's Individual Education Plan (IEP) and other individual education documents;
- Include in a final bill the Senate bill's requirement that schools hold a debriefing session with parents after restraint or seclusion has been used.

Elementary and Secondary Education Act (ESEA):

- Ensure that any changes to ESEA do not negatively impact students with disabilities, such as using the student's IEP for purposes of assessing adequate yearly progress;
- Require closer coordination of ESEA and IDEA policies;
- Substantially increase authorized funding for teacher preparation in the ESEA.

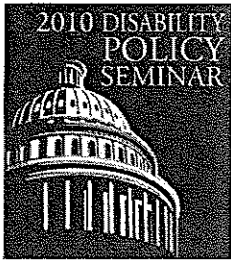
Relevant Committees

House Education and Labor Committee

Senate Health, Education, Labor and Pensions (HELP) Committee

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EMPLOYMENT

Background

Working age people with disabilities are among the most unemployed and underemployed segments of our society. The United States Bureau of Labor Statistics (BLS) reported that in January 2010, the percentage of people with disabilities in the labor force was 21.8% compared with 70.1% for persons with no disability. Far too many people with intellectual and developmental disabilities are underemployed and earn very little money. For example, according to the Government Accountability Office, 424,000 people are earning less than the federal minimum wage and of that number about 74% are people with intellectual disabilities. According to the Census Bureau, weekly wages for people with any disability decreased from \$353 in 2000 to \$288 in 2006. Weekly wages for people with an intellectual or developmental disability decreased from \$234 in 2000 to \$188 in 2006.

In response to the slow economic recovery and continued escalating unemployment, Congress and the Administration have proposed a number of tax bills and other proposals to stimulate private sector job creation. These bills have not targeted specific groups of people who are unemployed, such as people with disabilities but have been directed at encouraging employers to create new jobs.

The state vocational rehabilitation (VR) program is significantly under funded to meet the employment needs of hundreds of thousands of individuals with severe disabilities who need VR services to obtain employment. Many individuals with disabilities could also greatly benefit from the employment and training services delivered through the Workforce Investment Act (WIA) One-Stop system, though the WIA track record for serving people with disabilities is very poor. Physical and programmatic access to WIA services is woefully lacking for individuals with disabilities, despite Federal requirements that such services be accessible. In 2007, the state Developmental Disability Agencies provide day or employment supports to an estimated 566,895 individuals yet only 115,239 individuals were supported in integrated employment.

In each of the past three Congresses, bills to reauthorize WIA and VR have been introduced or discussed. A number of good provisions were included in these bills including strengthening transition services for special education students, expanding supported employment services and improving physical and programmatic access to one-stops.

Action Taken by Congress and the Administration

Legislation to reauthorize WIA and Vocational Rehabilitation has yet to be introduced in the 111th Congress. It was last reauthorized in 1998.

On the appropriations front, the President, like the previous Administration, proposed a consolidation of the Supported Employment State Grants Program and other programs with the Title I State Grant in his FY 2011 Budget Request. The proposed consolidation would provide no guarantee that the shifted funding would be utilized to provide supported employment services. The Administration also

proposed the Supported Employment Extended Services for Youth Grant program, a new competitive grant program to expand supported employment opportunities for youth with the most significant disabilities as they transition from school to the workforce. The recommended funding level is \$25 million for FY 2011.

Recommendations

The Congress should:

- Expand supported employment services by funding the President's proposal to create a new competitive grant program for youth with the most significant disabilities and by opposing the consolidation of the Supported Employment State Grants program;
- Increase funding for the VR and WIA system, including dedicated funding for transition services for students with disabilities who are graduating or exiting special education;
- Place a high priority on reauthorizing WIA and VR;
- Improve transition services by strengthening the VR role in the transition from school to adult life for students with disabilities, particularly requiring VR counselors to actively participate in the IEP process.
- Assure that people with disabilities have physical and programmatic access to the WIA system;
- Assure that WIA prioritizes services to people with disabilities and dedicates funding to those services.
- Ensure that people with disabilities are fully included in any efforts to create jobs and stimulate the economy.

Relevant Committees

House Appropriations Committee

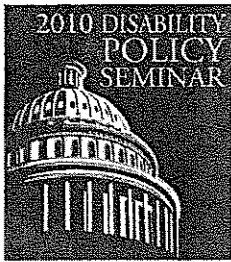
House Education and Labor (WIA and VR)

Senate Appropriations Committee

Senate Health, Education, Labor and Pensions (WIA and VR)

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Long-Term Services and Supports Provisions in Health Reform

Background:

Currently, there are approximately 10 million Americans in need of long-term services and supports (LTSS), and that number is expected to increase to nearly 15 million by the year 2020. Since private long-term care insurance coverage is limited, many people pay out of pocket and rely on unpaid family and friends to help provide support. Those with the most significant needs sometimes have no other alternative but to “spend down” their assets to qualify for Medicaid; they often remain impoverished for life to continue receiving support. With Medicaid already overburdened, this equation is not ideal and it is not sustainable.

The federal/state Medicaid program continues to be the major funding source for coverage of long term services and supports and continues to have an institutional bias. According to a study by Stephen Kaye published in a 2009 *Health Affairs* article, states that invested in Medicaid home and community-based services (HCBS), over a relatively short period of time, were able to slow their rate of Medicaid spending on long-term services. While the developmental disabilities service system has effectively used the Home and Community Based Services (HCBS) waiver to shift funding toward the community, this effort varies considerably among states. In addition, there are extensive waiting lists within states for community-based services and supports.

The **Patient Protection and Affordable Health Care Act** (P.L. 111-148) signed into law by President Obama and the **Health Care and Education Reconciliation Act of 2010** (H.R. 4872) which is awaiting signature include multiple provisions related to improving LTSS for people with disabilities of all ages. These provisions, described below, will not only increase independence, choice, and the ability to receive services in the community, but they also have the potential to reduce Medicaid costs and save states money over time.

Community Living Assistance Services and Supports (CLASS) Act

The CLASS Act will create a new national long-term care insurance program to help adults who have or who develop functional impairments to remain independent, employed, and engaged in their community. Financed by voluntary payroll deductions, enrollment in the CLASS program will be available to full and part-time working adults. It does not allow medical underwriting and exclusions based on pre-existing conditions (as found in private insurance plans). After a five year vesting period and a determination of eligibility based on functional need for assistance in Activities of Daily Living (ADLs), a recipient will have access to a cash benefit averaging \$75/day with no lifetime limit (the actual cash benefit will depend on the person's level of impairment). Counseling services will also be available to every beneficiary. The program is not means-tested – there will be no limits on individual income or assets and, if possible, the individual could continue to work. The CLASS program seeks to empower consumers: its flexible benefit could be utilized to meet an individual's particular needs, such as paying for personal assistance services or assistive devices or equipment.

The new law includes safeguards that ensure that no taxpayer dollars will be used and that the program will be solvent for at least 75 years, and includes language that allows the Secretary of HHS to provide additional safeguards as well. The Congressional Budget Office found that the CLASS program will also result in Medicaid savings over time. The CLASS program will assist people with disabilities and older Americans to maintain functional lives in their homes and communities.

Improvements to Medicaid Home and Community-Based Services (HCBS)

There are additional provisions in the health reform law that will increase access to HCBS. These provisions complement the CLASS program and each other, and are critically important elements of health care reform:

- **Community First Choice Option:** The Community First Choice Option is a new Medicaid state plan option for comprehensive HCBS for people with disabilities who are eligible for an institutional level of care. States that choose to provide services under the option will be required to make home and community-based attendant services and supports available to eligible individuals to assist them with activities of daily living, instrumental activities of daily living, and health-related tasks through hands-on assistance, supervision, or cueing. These states will be eligible for an additional 6 percent federal match rate for these services.
- **Removal of Barriers to Providing HCBS in the States:** These reforms remove certain barriers to providing Medicaid HCBS, primarily by making it easier for states to use a flexible state plan amendment option that has been available under current law (Medicaid Section 1915(i)). Specific changes include:
 - income eligibility criteria are aligned with other HCBS programs by permitting waiver-eligible enrollees to qualify for the option with incomes up to 300% of the federal Supplemental Security Income (SSI) level;
 - states will have greater flexibility to target certain populations in need, in part by waiving comparability requirements; and
 - limitations on the type and scope of services available have been removed.
- **State Balancing Incentives Program:** This program will temporarily increase the federal Medicaid matching rate for HCBS for states that undertake structural reforms to increase diversion from institutions and expand the number of people receiving HCBS. States which spend less than 50 percent of total LTSS funds on HCBS services will qualify for a 5 percent or 2 percent increase in federal match for HCBS services. Within 6 months, a selected state will need to adopt: a single point of entry system, case management services, a standardized assessment instrument for determining eligibility, a system for monitoring capacity, and a data collection infrastructure.
- **Spousal Impoverishment Protections for HCBS Beneficiaries:** Medicaid permits nursing home residents' spouses to keep one-half of the couple's assets, up to a ceiling. The maximum monthly income allowance is about \$2,700, while asset allowances range from about \$22,000 to \$110,000. This provision will apply those same rules to spouses of individuals receiving HCBS, helping to avoid spousal bankruptcy, splitting families apart, providing incentives for divorce, lawsuits, and other serious conflicts.
- **Additional Provisions:** The law extends the **Money Follows the Person Rebalancing Demonstration** through 2016 and expands funding for **Aging and Disability Resource Centers (ADRCs)**. The law also establishes a dedicated office to improve coordination of benefits for **persons eligible for both Medicare and Medicaid** (dual eligibles).

Direct Support Workers

The new law authorizes funding over 3 years for new training for direct care workers providing long term services and supports and creates a demonstration project to develop training and certification programs for personal or home care aids.

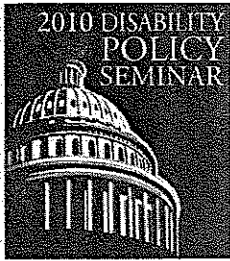
Action Taken by Congress and the Administration

Throughout the past year, enactment of comprehensive health care reform has been high on the Congressional agenda and was completed within the last month. The **Patient Protection and Affordable Health Care Act** (P.L. 111-148) was signed into law by President Obama on March 23 and the **Health Care and Education Reconciliation Act of 2010** (H.R. 4872) is awaiting signature as this goes to press.

Recommendations

Members of Congress should work with the Administration to ensure proper implementation of the new health reform laws. Congress should exercise its oversight authority to ensure that the new health reform laws operate as intended for people with disabilities.

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FY 2011 BUDGET AND APPROPRIATIONS

Background

On February 1, President Obama transmitted his \$3.8 trillion Fiscal Year (FY) 2011 budget request to Congress. Several days before the release of the budget, President Obama announced a three-year overall freeze in discretionary spending except for those related to defense and national security. Correspondingly, the President's budget request level-funds most disability related programs, provides small increases for some priorities and cuts or consolidates others.

Included in the freeze are all the Developmental Disabilities Act programs (University Centers for Excellence, DD Councils, and Protection & Advocacy). President Obama's 2011 education budget focuses on K-12 elementary and secondary education in anticipation of the reauthorization of the Elementary and Secondary Education Act (ESEA, formerly NCLB) with increased competitive funding to encourage academic reforms. However, special education programs continue to be underfunded, as the budget proposes very small increases for the Individuals with Disabilities Education Act (IDEA) state grant; and, in spite of the overwhelming scientific evidence about the positive effects of providing early intervention, the Preschool Grant and the Part C Early Intervention programs are flat-funded. In a significant disappointment, the President's budget seeks a deep reduction for the HUD Section 811 Supportive Housing for Persons with Disabilities Program. Section 811 provides competitive grants to non-profits to build or rehabilitate affordable and accessible units for non-elderly low-income persons with significant disabilities.

On the positive side, the President's budget supports many health-related programs important to people with disabilities, such as extending the increased Medicaid match provided in the Recovery Act (ARRA) and supporting increased funding for Social Security Administration to cover the on-going costs of administering the programs and efforts to reduce the backlogs in decisions on disability claims. The Administration also proposed the Supported Employment Extended Services for Youth Grant program, a new competitive grant program to expand supported employment opportunities for youth with the most significant disabilities as they transition from school to the workforce.

The President's budget request is only the first step in an almost year-long process of completing annual appropriations for federal department programs. The next step is for the House and Senate Budget Committees to begin crafting the Fiscal Year 2011 Budget Resolution (BR). The BR, once adopted by the Congress, will serve as the blueprint which the Appropriations Committees will use to make program by program spending decisions.

In addition to submitting the budget request to Congress, on February 18, the President signed an executive order establishing a new, bipartisan National Commission on Fiscal Responsibility and Reform. The Commission's objective is to put forward proposals to balance the budget (excluding interest payments on the debt) by 2015 and to improve the long-term fiscal outlook (reducing the deficit to 3 percent of GDP). The Commission will also examine changes to address the growth of entitlement spending, which includes programs that people with disabilities rely on such as Social Security, Medicaid, and Medicare.

Action Taken by Congress and the Administration

Following the release of the Obama Administration budget on February 1, the Congressional committees with jurisdiction over the Federal budget and appropriations process have been side tracked by health care reform. The various Obama Cabinet members have presented testimony in defense of the Administration's proposal.

Work on the FY 2011 Budget Resolution is expected to start in mid-April.

Recommendations

- Adopt a FY 2011 Budget Resolution that allows for the expansion of disability discretionary programs, strengthens entitlement programs and supports the recently enacted reforms to health care and long term services and supports;
- Increase FY 2011 appropriations for key disability programs in accordance with the recommendations in the table below; and
- Increase funding for the Social Security Administration and those federal government agencies that enforce disability rights.

The following table compares FY 2010 appropriations and the President's request for key disability programs with our recommendations for FY 2011 funding.

Table Comparing FY 2010, President's Budget and Our Recommendations (In Millions)	Final FY 2010	President's FY 2011 Budget	FY 2011 Recommendation
IDEA Part B State and Local Grants	11,505.0	11,755.0	12,755.0
Preschool Grants	374.0	374.0	450.0
Part C Early Intervention	440.0	440.0	520.0
State Personnel Development	48.0	48.0	55.0
Technical Assistance and Dissemination	49.5	49.5	55.0
Personnel Preparation	91.0	91.0	100.0
Higher Ed. Demonstration Projects-Disability	7.0	7.0	10.0
Postsecondary Program for Students with ID	11.0	11.0	14.0
University Centers for Excellence in DD	38.9	38.9	44.0
Developmental Disabilities Councils	75.1	75.1	78.0
Protection & Advocacy Systems	41.0	41.0	46.0
Projects of National Significance	14.0	14.0	16.0
Maternal & Child Health Block Grant	662.1	673.0	730.0
Combating Autism Act – Autism and Other DD	48.0	55.0	55.0
Center on Birth Defects & DD	143.4	143.5	150.0
Natl. Institute of Child Health and Hum. Dev.	1,329.5	1,369.5	1,643.4
Lifespan Respite Care Act	2.5	5.0	98.0
Office of Disability Employment Policy	39.0	39.0	48.0
Voc. Rehabilitation State Grant	3,084.6	3,141.5	3,141.5
Supported Employment State Grant	29.2	0.0	50.0
Supported Employment Extended Services Youth	<i>new</i>	25.0	25.0
NIDRR	109.2	112.0	120.0
State Assistive Technology Programs	31.0	31.0	32.0
Independent Living Formula Grants	104.0	110.0	115.0
Social Security Administrative Expenses	11,598	12,528	12,528.0

Relevant Committees

House and Senate Labor, Health and Human Services Subcommittees
House and Senate Budget Committees

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ACHIEVING A BETTER LIFE EXPERIENCE ACT OF 2009 **(ABLE Act) S. 493/H.R. 1205**

Background

Many families have been searching for a way to plan for the future of a child with severe disabilities. While they are able to save for the educational needs of their other children through "529" college tuition plans, they find that those plans do not fit the needs of their child with severe disabilities. Since their children may now, or in adulthood, need the long term services and supports of the Medicaid program and the income assistance of the Supplemental Security Income (SSI) program, many have considered using the existing options for supplemental needs planning in the Medicaid program. However, often families have found it to be too expensive to hire an attorney to establish a trust which meets the requirements of the Medicaid and SSI programs. These families recognize that their loved ones may live for many decades beyond the ability of the parents or other family members to assist them through supplementing services they receive through Medicaid. Others want to ensure the financial security of family members who have the level of disability required for Medicaid eligibility, but for now, are managing to function without the use of those benefits. Still others want to ensure that their family member can exercise control over the funds in the account without endangering the Medicaid and SSI benefits on which they may rely.

Achieving a Better Life Experience Act of 2009 (ABLE Act)

The ABLE Act would give individuals with disabilities and/or their families access to savings accounts that would allow individual choice and control while protecting eligibility for Medicaid, SSI, and other important federal benefits for people with disabilities. They could create a disability savings account that would accrue interest tax-free. Withdrawals would not be taxed as long as they are used to pay for qualified expenses. The account could fund a variety of essential expenses for the person with a disability, including educational expenses; medical and dental care; health, prevention, and wellness expenditures; employment training and support; assistive technology; personal supports services; transportation; housing; and other expenses for life necessities.

Savings accounts opened under the ABLE Act would differ from other savings instruments with tax advantages because they provide substantial flexibility:

- The individual with disabilities could hold/control the account, or parents or a guardian could hold it in trust.
- The allowed expenses are designed to be broad enough to accommodate the individual needs of account-holders.
- Most of the allowed expenditures are not limited to adulthood or retirement age, so they can be used whenever they are needed.
- The flexibility in expenses also allows families to save with confidence even though they cannot always predict how independent their child will become.

- A family with money in a traditional account saved for a child who becomes disabled later in life can roll-over the funds into a disability savings account without penalty.
- The account would be easy and inexpensive to open, like a simple IRA account.
- Unlike some savings instruments, such as “529” college accounts, the ABLE Act accounts would be created and regulated on the federal level, ensuring that they are portable for individuals and families who move across state lines.
- Individuals and families who find that the current individual or pooled trusts available under the Medicaid program will better address their needs may roll-over the account into the trusts.
- The ABLE accounts can be managed by pooled trusts, if the individual or family so choose.

In a manner similar to the treatment of Medicaid trusts, funds remaining in the accounts at the individual’s death would be used to “pay-back” the state Medicaid program up to the value of services provided to the individual during life.

The ABLE Act would give individuals with disabilities and their families an option for saving for their future financial needs in a way that supports their unique situation and makes it more feasible to live full, productive lives in their communities.

Action Taken by Congress and the Administration

The ABLE Act was introduced in the House (H.R. 1205) by Representatives Crenshaw (R-FL), Meek (D-FL), and Kennedy (D-RI), and McMorris Rodgers (R-WA), and in the Senate (S. 493) by Senators Casey (D-PA), Hatch (R-UT), Dodd (D-CT), Brownback (R-KS), and Burr (R-NC). Both bills have a growing bipartisan list of co-sponsors. No hearings have yet been held.

Recommendations

Members of Congress are urged to co-sponsor the ABLE Act and to urge Committee action and passage of the bills.

Relevant Committees

Senate Finance Committee
House Ways and Means Committee
House Energy and Commerce Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

3/30/10



THE ARC, AAIDD, AUCD,
UCP, NACDD AND SABE

FACT SHEET

HEALTH CARE REFORM

Background

The Patient Protection and Affordable Care Act (P.L. 111-148) and the Health Care and Education Affordability Reconciliation Act (H.R. 4872) will provide access to affordable health insurance for 32 million Americans who are currently uninsured. According to the non-partisan Congressional Budget Office, P.L. 111-148 and the Reconciliation bill will reduce the federal deficit by \$130 billion over the first ten years and \$1.2 trillion over the second ten years. The law represents a sea change in expanding access to affordable, quality health care for persons with disabilities.

Insurance Market Reforms - the law will:

- Prohibit pre-existing condition exclusions, lifetime and annual caps, discrimination based on disability and health status, and rescission of coverage;
- Require guaranteed issue and renewal of insurance policies.

Expanding Access to Coverage

- Establish a temporary high risk pool to provide coverage to those who are currently uninsured. This high risk pool will expire when the new Insurance Market Exchange becomes effective on 1/1/14.
- Provide significant subsidies to assist low income individuals to purchase coverage in the Exchange;
- Include coverage of dental and vision care for children in the Exchange;
- Include coverage of critical disability-related services, such as mental health services, rehabilitative and habilitative services and devices, in the Exchange.

Medicaid

- Expands Medicaid eligibility to 133 per cent of the federal poverty level with significant federal funding;
- Increases Medicaid reimbursement for physicians and pediatricians to Medicare rates in 2013 and 2014 with full federal funding.

Medicare

- Improves care coordination for dual eligibles (those who receive both Medicare and Medicaid benefits) by creating a new "Federal Coordinated Health Care Office" within the Centers for Medicare and Medicaid Services (CMS);

Data Collection and Disparities for Persons with Disabilities

- Requires the Secretary of the U.S. Department of Health and Human Services to:
 - Locate where persons with disabilities access primary, acute, and long-term care;
 - Determine the number of providers with accessible facilities and equipment to meet the needs of individuals with disabilities;
 - Determine the number of Employees of health care providers trained in disability awareness and patient care of individuals with disabilities.

The Secretary of HHS, through the National Coordinator for Health Information Technology will analyze the data for trends in health disparities and make reports available.

- Require any federally conducted or supported health care or public health program, activity or survey to collect and report to the extent practicable data on disability status, including disability subgroups (using oversampling if needed).

Prevention

Identifies meeting the needs of persons with disabilities as a specific activity of the “Community Transformation Grants”, a new competitive grant program where communities will be awarded grants to promote individual and community wellness and reduce the incidence of chronic diseases associated with overweight people who are obese, or use tobacco.

Provider Training

Increases opportunities for training of health care providers, including dentists, on the needs of persons with disabilities, including those with developmental disabilities.

Action Taken by Congress and the Administration

Throughout the past year, enactment of comprehensive health care reform has been high on the Congressional agenda and was completed within the last month. The **Patient Protection and Affordable Health Care Act** (P.L. 111-148) was signed into law by President Obama on March 23 and the **Health Care and Education Reconciliation Act of 2010** (H.R. 4872) on March 30.

Recommendations

Members of Congress should work with the Administration to ensure proper implementation of the new health reform laws. Congress should exercise its oversight authority to ensure that the new health reform laws operate as intended for people with disabilities.

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.



THE ARC, AAIDD, AUCD,
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FACT SHEET

MODERNIZATION OF DISABILITY TERMINOLOGY

Background

Over the past several decades, the field of disability has experienced numerous changes, including the identification of new disabilities, new civil rights protections, a growing self advocacy movement and a shift in how society views disability. Within the field of intellectual disabilities, there has occurred a gradual shift in the terminology to define this population. The terms "mental retardation" and "mentally retarded" have been replaced in many arenas with the terms "intellectual disability" and "intellectually disabled". Unfortunately, common usage of the terms "retarded" and "retard" are heard in everyday language and the media, including popular movies. People with intellectual disabilities and their families are insulted and offended by such actions.

Professional and advocacy organizations working on behalf of people with intellectual disabilities have changed the names of their organizations. Many states have or are in the process of changing state laws and the names of state agencies that serve this constituency.

Many federal laws require that applicants for services, benefits and rights are identified as having a particular disability. Most of these laws require a label of "mental retardation" to establish eligibility.

Action Taken by Congress and the Administration

Senator Barbara Mikulski (D-MD) introduced S.2781, named Rosa's Law. This bill now has 38 bipartisan co-sponsors. Representative Michael McMahon (D-NY) introduced H.R.4544. It is named the Elizabeth A. Connelly Act. This bill now has 2 co-sponsors. The bills are virtually identical. Both bills would change the terms "mental retardation" and "mentally retarded" to "intellectual disability" and "intellectually disabled" in laws primarily related to education, employment and other social services. The legislation would not affect in any way eligibility or services under the programs within the reach of the bill.

Recommendations

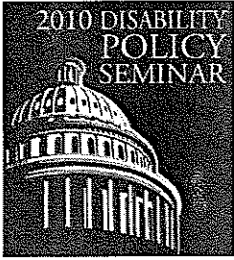
Disability advocates, particularly self advocates with intellectual disabilities, and their families strongly desire that the terms "mental retardation" and "mentally retarded" be replaced in federal laws. They urge all Members of Congress to co-sponsor this legislation so that it could become law this year. They also urge the Senate Health, Education, Labor and Pensions Committee (HELP) and the House Education and Labor Committee to move the bills to the House and Senate floors for a final vote.

Relevant Committees

Senate Health, Education, Labor and Pensions Committee
House Education and Labor Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.

3/30/10



THE ARC, AAIDD, AUCD,
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FACT SHEET

DIRECT SUPPORT WORKERS

Background

For millions of people with disabilities of all ages, direct support professionals are the key to living successfully in their home communities. Direct support professionals (DSPs) are personal care assistants, home care aides, or staff in community residential supports programs that assist people with disabilities with medications, preparing and eating meals, dressing, mobility, and handling daily affairs.

Unfortunately, there is a crisis in the availability of professionals to provide these direct supports. The average hourly wage for a direct support professional is \$9.85 compared to the average hourly wage for DSPs employed by a state government of \$15.48. The U. S. Bureau of Labor Statistics projects the demand for this workforce to increase more than 41% between 2004 and 2014, despite the worsening economy. Many workers find that they can earn higher hourly wages and receive better benefits in far less demanding jobs in the fast food and the retail industries. As a result, people with disabilities experience continuous turnover of direct support workers or they find themselves unable to get workers at all. Unable to obtain adequate assistance, people find their health, safety, and sometimes, their lives in jeopardy.

Self-advocates, families, advocates, and service providers have worked for decades to ensure successful community living for all people with disabilities. When there is safety and security in community based services and supports, people do better. Workers in the least desirable service setting - state-run institutions - are generally paid higher wages and receive better benefits than their counterparts providing highly valued community-based services and supports.

Organizations providing community-based supports must work within the constraints imposed by policies of state governments which establish the reimbursement rates for services available in the Medicaid program. Otherwise, the providers have to find sources of funding elsewhere, and while many do raise funds to pay staff, most find it difficult to do so for this public responsibility.

Representatives Lois Capps (D-CA) and Lee Terry (R-NE) introduced H.R. 868, the Direct Support Professionals Fairness and Security Act. The bill would take important steps to ensure that direct support professionals are paid wages and benefits that enable them to stay in their jobs and provide the critical services that people with disabilities rely upon.

The direct support worker bill would amend the Medicaid program (Title XIX of the Social Security Act) to provide funds to States to enable them to increase the wages paid to targeted direct support professionals in providing services to individuals with disabilities. The program is designed as an option to states and would provide enhanced federal medical assistance percentage (FMAP) for five years to states to increase wages. It is designed to increase wages and eliminate the gap between wages paid to private employees and wages paid to public employees in the state.

In order to receive the enhanced FMAP, states would be required to submit a five-year plan and would have to assure continuation of the increased wage rate after the five-year period. The state plan must be developed in conjunction with individuals with disabilities and family members, private providers, and direct support professionals.

The bill targets the increased FMAP to cover direct support professionals working for private employers who provide supports and services to people with disabilities who are eligible for and receiving Medicaid under the following state plan services: personal care option for personal assistance; rehabilitation option for rehabilitation or habilitation; home health services; home and community-based services under Section 1915(c) or Section 1115 waivers; intermediate care facility services for persons with mental retardation and related conditions (ICFs/MR) and 1915(j) home and community based state plan option and the 1915 (i) self directed personal assistance state plan option.

The Administration and many in Congress are looking for ways to limit the Medicaid program. However, without enactment of this legislation, people with disabilities who need direct supports will continue to be made more vulnerable by the failure of the system to pay direct support professionals a decent wage with critical health care and other benefits. If people with disabilities cannot find community services they could be forced into institutional settings which will increase Medicaid spending.

Action Taken by Congress and the Administration

H. R. 868 was introduced in the House of Representatives by Rep. Lois Capps (D-CA) and Rep. Lee Terry (R-NE). There are currently 61 cosponsors. A lead sponsor for the Senate bill has yet to be identified.

Recommendations

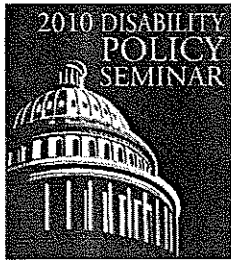
Disability advocates should commend Representatives Capps and Terry for their leadership and commitment to ensuring that people with disabilities are not made more vulnerable by the failure of the system to pay direct support professionals a decent wage with critical health care and other benefits. Members of the 111th Congress who have not done so should be urged to co-sponsor H.R. 868. Senators should be encouraged to sponsor a Senate companion bill.

Relevant Committees

Senate Finance Committee

House Energy and Commerce Committee (Subcommittee on Health)

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.



THE ARC, AAIDD, AUCD,
UCP, NACDD AND SABE

FACT SHEET

AUTISM SPECTRUM DISORDER (ASD)

Background

According to the Centers for Disease Control and Prevention (CDC), the prevalence of Autism Spectrum Disorders (ASD) could be as many as 1 in every 100 American children. Continued research is needed to document trends in the growth of ASD, as well as research into and development of effective interventions. In 2006, President Bush signed into law the Combating Autism Act (CAA, PL 109-416). This law is unique in that it is wide-reaching by targeting and coordinating every available system in order to efficiently and effectively address this developmental disability that now affects one percent of the American population. The law focused on expanding research and coordination at the National Institutes of Health (NIH), increasing awareness and surveillance at the Center for Disease Control (CDC), and expanding the interdisciplinary training of health professionals to identify and support children with ASD and their families. This law will be up for reauthorization in 2011. Several provisions will expire if the law is not reauthorized in a timely manner.

While the CAA supported more efforts into research and surveillance, greater commitments are also needed to expand access to services for those with ASD. Services that are desperately needed include early intervention, education, supported employment, transition services and family supports. Individuals with ASD and their families need access to accurate information about scientifically-supported interventions. The training of a wide range of interdisciplinary professionals to provide these services must also be a top priority. A well-trained workforce will ensure that the findings coming out of our research institutions can be translated and made available to parents and providers across the country, and will ensure that services can be implemented as quickly as possible.

Action Taken by Congress and the Administration

On April 2, 2009, Sens. Durbin (D-IL), Casey (D-PA), and Menendez (D-NJ) introduced the *Autism Treatment Acceleration Act* (S. 819). A companion bill was introduced in the House (H.R. 2413) by Reps. Doyle (D-PA) and Smith (R-NJ). This bill would accelerate the development of a service system to meet the needs of individuals with ASD and related developmental disabilities.

The bill creates demonstration projects to increase access to quality health care services and coordination of care, as well as to develop and provide an array of services to adults with ASD; establishes a national network to link research and service initiatives at the federal, regional, state

and local levels; and establishes a multiyear national training initiative on autism and a technical assistance center to significantly develop and expand interdisciplinary training and continuing education on ASD.

A requirement that health insurers cover the diagnosis and treatment of autism spectrum disorders, including Applied Behavior Analysis, assistive communication devices and other effective treatments is also added.

Recommendations

The 111th Congress should:

- Reauthorize and fully fund the Combating Autism Act
- Support the Autism Treatment Acceleration Act and other legislation that addresses the direct service and interdisciplinary training needs associated with the increasing number of individuals with Autism Spectrum Disorders.

Relevant Committees

House and Senate Appropriations Committees

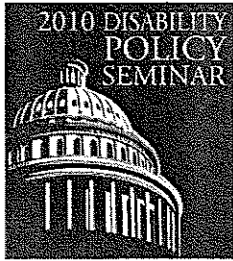
Senate Health, Education, Labor and Pensions Committee

House Energy and Commerce Committee (Subcommittee on Health)

House and Senate Labor, Health and Human Services and Education Appropriations
Subcommittees

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202-783-2229), Association of University Centers on Disabilities (301-588-8252), AAIDD (202-387-1968), or National Association of Councils on Developmental Disabilities (703-739-4400), or SABE (phone).

4/12/10



THE ARC, AAIDD, AUCD,
UCP, NACDD AND SABLE

FACT SHEET

HOUSING FOR PEOPLE WITH DISABILITIES: THE CRISIS AND THE OPPORTUNITY

Background

Being part of the community and living as independently as possible are among the most important values and goals shared by people with disabilities, their families, and advocates. A home of one's own – either rented or owned – is the cornerstone of independence for people with disabilities. However, across the nation, people with developmental and related disabilities face a severe crisis in the availability of decent, safe, affordable, and accessible housing. Today many still live in large congregate facilities or other inappropriate places like institutions. Over 700,000 people with developmental disabilities live with aging parents (one of whom is over age 65). For people who use wheelchairs or other mobility devices, finding housing with even basic accessibility features (e.g. an entrance with no steps) ranges from daunting to impossible.

The affordability gap for people with disabilities has exponentially worsened in recent years. According to *Priced Out in 2008*, on a national average, over 4 million Americans with disabilities who rely on federal monthly Supplemental Security Income (SSI) of \$674 for all their basic needs would have to pay 112.1 percent of their entire monthly income to rent a modest one-bedroom unit. The cost of renting a smaller studio/efficiency unit is 99.3% of monthly SSI.

Action Taken by Congress and the Administration

Section 811 Supportive Housing for Persons with Disabilities Program

HUD's Section 811 provides housing for people with physical or developmental disabilities, or people with chronic mental illness who are 18 years of age or older and have very low incomes (at or below 50 percent of the area median income). Section 811 participants may live in supportive housing units developed and owned by non-profit organizations, or they may receive tenant-based rental assistance that helps them rent decent, accessible and safe housing in the private rental market. Tenants pay 30 percent of their adjusted income for rent which ensures affordability for those receiving SSI benefits.

Section 811 is the only HUD program that produces affordable and accessible housing for non-elderly people with disabilities. Historically HUD has used Section 811 funds to provide interest-free capital funding to non-profit sponsors to help finance the development of fully accessible rental housing – primarily independent living projects and small group homes – many of which offer voluntary supportive services for people with significant disabilities. A project-based contract (also known as a PRAC) is linked to the capital funding to cover housing operating costs such as insurance and maintenance. The Section 811 law also allows HUD to use up to 25 percent of the program's funds for tenant-based rental assistance (known as the "Mainstream Housing Opportunity for People with Disabilities" voucher program). Renewal funding for these 14,000 vouchers is "taken off the top" of each year's Section 811 appropriation and in FY 2011 is expected to cost \$113 million of Section 811's small \$300 million budget. All Section 811 stakeholders agree that the program needs to be reformed to survive and meet the needs of people with disabilities for supportive housing.

The Administration's FY 2011 budget proposes to eliminate all funding for construction of new 811 units because, according to the budget's justification, the program needs to be reformed to leverage non-811 sources of capital to build units. Congress is making progress on a comprehensive 811 reform bill.

In July of 2009, the House of Representatives overwhelmingly passed the Frank Melville Supportive Housing Investment Act (H.R. 1675) and Sens. Robert Menendez (D-NJ) and Mike Johanns (R-NE) have introduced an identical bill (S.1481). This groundbreaking legislation streamlines Section 811 processing requirements, removes outdated regulatory barriers, transfers funding for the "Mainstream" voucher program to the Section 8 voucher program and – most importantly – authorizes a new PRAC-Only Demonstration program. This Demonstration program will provide the essential rental subsidy to reduce rents to affordable levels for people receiving SSI in a small but significant percentage of the hundreds of thousands of units that are routinely created every year through the Low Income Housing Tax Credit Program (LIHTC) and HOME programs administered by states and local jurisdictions. By using LIHTC, HOME, or other federal or state funds to pay construction costs and the PRAC to pay for operating costs, this Demonstration program will keep 811 units affordable to SSI beneficiaries, significantly increase integrated housing opportunities, and triple the number of 811 units funded without increasing the program's appropriation.

Section 8 Rental Assistance – Section 8 Housing Choice Voucher Program

Section 8 vouchers, which are administered by Public Housing Agencies (PHAs), are designed to bridge the gap between income and rent by paying the difference between what a very low-income household can afford (e.g., 30 percent of income) and modest rental housing costs. Unfortunately, non-elderly adults with disabilities comprise only 19% of all Section 8 voucher holders – far less than their relative need for assistance. Congress provided no funding for new vouchers in FY 2010 and the President's FY 2011 budget proposes no new funding for these vouchers.

Increasing Production of Affordable and Accessible Housing/

The National Affordable Housing Trust Fund Act was enacted in 2008 to establish dedicated funding for the production, preservation and rehabilitation of 1.5 million affordable homes over 10 years. At least 67.5% of the funds must be spent on rental housing for extremely low income households with incomes at or below 30% of median income. SSI payments are equal to only 18 percent of median income. This new rental housing production program could significantly expand the supply of deeply affordable and accessible rental housing units for people with disabilities with the lowest incomes. President Obama's FY 2011 budget requests \$1 billion for the National Affordable Housing Trust Fund.

Recommendations

- Restore the cut in the Section 811 production program to bring funding to \$300 million, provide at least \$30 million for new Section 8 vouchers targeted to non-elderly persons with disabilities, and support President Obama's request for \$1 billion for the National Affordable Housing Trust Fund; and
- Senators should co-sponsor the Frank Melville Supportive Housing Investment Act of 2009 (S.1481).

Relevant Committees

House & Senate Appropriations Committees
House Committee on Financial Services
Senate Banking, Housing and Urban Affairs Committee

For more information, please contact The Arc and United Cerebral Palsy Disability Policy Collaboration (202) 783-2229, Association of University Centers on Disability (301) 588-8252, American Association on Intellectual and Developmental Disabilities (202) 387-1968, National Association of Councils on Developmental Disabilities (202) 506-5813 or the Self Advocates Becoming Empowered (802) 760-8856.